PULMONARY HYPERTENSION
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Canada's Drug Agency: Feedback on Evolving Patient Group Input Submissions into the Drug Reimbursement Review Process

Submitted via online form: https://www.cda-amc.ca/feedback-evolving-patient-group-input-submissions-drug-reimbursement-review-process

Questions for Feedback

1. Input for the Deliberative Framework

1.1 What suggestions do you have for evolving the patient input process to focus on what is needed to support deliberations on the deliberative framework domains? (Clinical Value, Unmet Clinical Need, Distinct Social and Ethical Considerations, Economic Considerations, and Impacts on Health Systems)

As mentioned in our previous consultation submission, we commend the inclusion of the deliberative framework and decision flow chart clarifying domains beyond the economic, but we repeat that the relative weighting should be stated explicitly and, ideally, standardized, so patient groups have a better sense of where their input might be most useful.

We also commend the inclusion of a non-disease-specific patient representative on review committees to ensure committees have someone whose role is to attend to social and/or equity-related perspective gaps, and the provision of orientation and training for all review committee members on how to interact respectfully with people with lived experience.

The inclusion of content from presentations by persons with lived experience at committee meetings is, again, an important step towards a practice more inclusive of patient group information. We encourage close collaboration with patient groups in identifying an appropriate presenter with lived experience. The offer of honoraria, guidance to that person in preparing their presentation, and an emotional debrief afterwards, both helps level the playing field for such presenters and recognizes the emotional labour involved in presenting one's lived experience. For in-person meetings, financial and logistical help with accommodation, travel, etc. would be essential. For both virtual and in-person meetings we ask that the presenter with lived experience be allowed to be accompanied by a support person (e.g., a caregiver or patient group representative). Financial and logistical help should be offered to the support person as well.

In future, we suggest the CDA consider hearing from more than one patient representative voice. Including one sole person's voice raises questions about equity and inclusion in both the process of choosing the representative and in who, ultimately, is chosen to speak. Per the March 6 CDA webinar, we recognize that thus far the CDA has not thus far been in a position where a nomination process has been necessary, but as the patient input process evolves, we recommend the creation of a transparent nomination process to partially address equity issues.

2. Input Collection and Submission Methods

2.1 What are your ideas and suggestions for methods (e.g., surveys, interviews, focus groups, videos, other) you think work well to collect patient perspectives? Please explain why.

We feel that the most equitable and inclusive approach is to offer a variety of synchronous and asynchronous methods incorporating both written and verbal options. Patients with limited energy, such as pulmonary hypertension patients, may need to conserve their energy. In some cases, this will mean patients prefer the faster option of a spoken response or a video submission; in others, it will mean patients prefer to compose a written response at a time or times of their choosing.

2.2 What are your ideas and suggestions for formats (e.g., written input template, verbal input, targeted input questions, open-ended questions, broad questions, a combination of these) you think work well to submit patient group input? Please explain why.

We consider there is a need to think about inclusivity here as well: given the variable size, resourcing, and experience of patient groups, we suggest a combination approach. Templates and targeted questions will help direct patient groups' focus toward issues the CDA considers the most relevant, while broad and open-ended questions will allow patient groups to alert the CDA to wider issues or topics that the guided questions may have missed. Again, options for both verbal and written input would allow a wider variety of patient organizations to be able to offer input.

3. Input Submission Communication and Guidance

3.1 What guidance, communication, or tools would make the input process easier for you (e.g., video guide[s], learning sessions, guidance document, tool kit, other)?

Learning sessions on developing an effective submission would be generally useful. As an experienced patient group, PHA Canada would likely find a guidance document the most directly useful tool. However, because of our good experiences with the CDA's webinars, which we find tend to provide an excellent summary of the documentation as well as the opportunity to ask questions and have them answered, we would also likely attend the learning sessions if they were offered.

An opportunity to ask follow-up questions (and receive timely responses) via email or telephone during the input period would be valuable.

Equitable funding for patient groups with less experience and/or fewer resources – small groups for rare diseases, for example -- is necessary to ensure equitable participation in the drug review process.

3.2 What type of feedback would you like to receive on your input submission?

We would like emailed confirmation of receipt of our feedback. In addition, while we recognize CDA's resourced are limited, patient groups do require substantive feedback in order to improve future input and better serve patients.

3.3 How would you like to receive feedback on your input submission?

A document summarizing all the submissions received would provide a useful measure of where our feedback fell in the spectrum of submissions and where it was incorporated into decision-making. To be inclusive, it should be accompanied by an explanatory webinar and a plain-language summary. The existing practice of including patient group and clinician group input by topic in the Review Report may mitigate the need for a separate feedback summary, but we encourage the use of plain language in all reports.

4. Other

4.1 Do you have any comments or suggestions we should consider in evolving patient group input into drug reimbursement reviews that was not captured in the previous questions?

Small nonprofit patient groups, who may not be able to quickly coordinate their response, would benefit from an input submission window longer than six weeks.

We hope CDA will work with other federal agencies to improve input alignment and to shorten the overall process and reduce the burden on patient organizations that are submitting to several agencies.

We appreciate CDA's commitment to continuously evolving the patient group input process – listening, asking, and giving feedback in an iterative process.

We look forward to further developments.